

Caring for People with Severe ME/CFS

Dear Healthcare Professional:

The purpose of this letter is to provide guidance on the management of severe ME/CFS. Since recent studies suggest that Long Covid presents with a constellation of symptoms similar to ME/CFS, this guidance may provide direction for severely affected Long Covid patients as well.

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex, chronic disease that most often follows a virus or other infection and is associated with neurological, immunological, autonomic, and energy metabolism dysregulation. Patients experience sleep dysfunction, cognitive impairment, orthostatic intolerance, pain, gastrointestinal issues, sensory sensitivities, other bodily symptoms, and post-exertional malaise (PEM). The hallmark PEM is a further worsening of symptoms and function following previously tolerated physical or cognitive exertion or sensory, emotional, orthostatic and other stressors. While the disease may wax and wane, recovery is rare, and patients can be ill for years or decades.

ME/CFS results in substantial functional impairment and disability, *with an estimated 25% of those affected being homebound or bedbound*. The most severe patients require total care supported by in-home clinical care and services.

Due to a lack of medical awareness and education, most people with ME/CFS remain undiagnosed and struggle to find knowledgeable medical providers, let alone someone able to provide care in their homes. As a result, the most severe ME/CFS patients are largely invisible to the medical community because they are too ill to go to the clinic. These underserved patients are in critical need of home-based clinical care and a compassionate medical provider can make a significant difference in their lives.

Prior to SARS-CoV-2, ME/CFS was estimated to affect 1-2.5 million Americans. These numbers are expected to rise significantly as people are reporting lingering symptoms similar to ME/CFS following COVID and some have already been diagnosed with ME/CFS.

The following summarizes recommendations for the clinical care of people with severe ME/CFS . If you currently have ME/CFS patients in your practice, we encourage you to evaluate their level of disease severity and functioning and what additional support they may require, including in-home clinical care, services, and other forms of support. For your Long COVID patients or others presenting with severe functional impairment and a range of symptoms across systems, we encourage you to consider ME/CFS in the differential diagnosis of these patients.

Respectfully,

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Overview of Clinical Care of People with Severe ME/CFS

Bateman et al. (1) have published guidance for the diagnosis and management of ME/CFS that is useful for all levels of severity of ME/CFS and also provides background on the nature of the disease and what's known about the underlying pathology. The following is specific to the care and management of severe ME/CFS – those patients who are homebound or bedbound as a result of ME/CFS - and summarizes recommendations provided by Montoya et al (2). Additional information on caring for the severely ill, including in children, is available in the resources listed below:

Care Principles

Because they are homebound or bedbound, medical providers have often not seen or treated people with severe ME/CFS. The most important things providers can do are:

- Accept the patient's reports of their illness experience, particularly around exertional and sensory limits and PEM. How they present is usually a poor indicator of their overall health.
- Respect the severity and multi-system nature of ME/CFS. Standards of care used in other chronic illnesses, such as graded exercise or increasing activity, may result in harm from exceeding the patient's narrow exertional and sensory limits.
- Provide clinical care and services in the home where the patient's energy limits can best be managed. This can be facilitated via telehealth or proxy communication strategies such as allowing a caregiver to speak for the patient. Emergency rooms, hospitals, and even visits to healthcare providers' offices can exceed the patient's stringent exertional limits and cause a prolonged payback period due to PEM, or potentially permanently worsen their health.
- Partner with the patient and caregiver and coordinate across providers to achieve the required care, services, and support while not overloading the patient with excessive interactions, tests or outings (even outside of bed) that might exceed their limits.

Presentation in Severe ME/CFS

- Profound weakness, with some unable to move, communicate, or do any basic activities of daily living
- Severe, widespread, and often constant pain
- Hypersensitivities to sensory stimuli, esp. light, noise, touch, chemicals
- Cognitive issues that can be so severe as to impede the patient's ability to communicate, even with their caregiver
- Gastrointestinal issues that can significantly impede nutrition or require tube feeding
- Orthostatic intolerance that impedes upright posture, leaving many lying flat 20-24 hrs/day
- Extreme intolerance of even small amounts of exertion, including basic activities of daily living or mild sensory exposures. Exceeding patient limits can worsen other symptoms for days, weeks, months, or sometimes permanently

Evaluation

In addition to the general ME/CFS diagnostic methods, the following are key to evaluating severe ME/CFS and developing a care plan:

- Assess the patient's capacity to conduct activities of daily living and what activities overload their limited energy and result in a worsening of symptoms and function
- Assess and treat any medical issues such as untreated pain, sleep impairment, orthostatic intolerance, sensory sensitivities, or secondary psychiatric comorbidities such as depression or grief at loss of function. Be careful to not misattribute somatic symptoms to mental illness.
- Assess non-medical complicating factors, such as lack of a caretaker on in-home services, and advocate for the patients to ensure those needs are met

Management

The first principle of managing a person with severe ME/CFS is to create a quiet, stable environment in the home that limits the exertion and other stressors that can worsen their illness.

- Teach patients and their caregivers about PEM and the importance of energy conservation.
 - Restricting energy expenditure and sensory stimuli, often to an extreme degree, may be the only way to stabilize severe ME/CFS patients so they do not worsen over time. For the most severe patients, this may mean spending most or all of their days lying in a dark room with noise-canceling headphones.
 - Physical and occupational therapists with experience in ME/CFS can evaluate symptoms and activities/functioning, recommend symptom management and energy conservation approaches, and teach patients about PEM and pacing strategies.
- Judiciously prescribe pharmacological and non-pharmacological approaches to help minimize symptoms such as pain, orthostatic intolerance and sleep dysfunction, thereby improving a patient's quality of life.
 - No drugs have been approved specifically for ME/CFS but proactive use of off-label drugs to treat symptoms can improve symptoms and quality of life.
 - To avoid drug sensitivities, start low and go slow.
 - While oral hydration and nutrition is preferred, tube feeding, and intravenous saline can address nutritional and hydration needs while also conserving limited energy.
- Schedule regular home or telemedicine visits for ongoing care and to monitor changes in the patient's health.
- Partner with allied health professionals, such as visiting nurses and other home care providers, to provide needed home-based care and services and mitigate against the risk of prolonged crashes that could result from trips to the doctor's office or emergency room.
- If hospitalization is unavoidable, ensure hospital staff understand the nature of severe ME/CFS and provide an appropriate environment that minimizes interaction, intrusion, chemical exposure, sensory stimulation, and orthostatic and exertional stressors.

Resources:

1. Bateman L, Basted AC, Bonilla HF, Chheda BV, Chu L, Curtin JM, et al. Myalgic encephalomyelitis/chronic fatigue syndrome: Essentials of diagnosis and management. *Mayo Clinic Proceedings* 2021;96(11):2861-78. [https://www.mayoclinicproceedings.org/article/S0025-6196\(21\)00513-9/fulltext](https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext)
2. Montoya JG, Dowell TG, Mooney AE, Dimmock ME, Chu L. Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Healthcare*. 2021; 9(10):1331. <https://doi.org/10.3390/healthcare9101331>
3. Rowe, P.C.; Underhill, R.A.; Friedman, K.J.; Gurwitt, A.; Medow, M.S.; Schwartz, M.S.; Speight, N.; Stewart, J.M.; Vallings, R.; Rowe, K.S. Myalgic encephalomyelitis/chronic fatigue syndrome diagnosis and management in young people: A primer. *Front. Pediatr.* **2017**, *5*, 121 <https://www.frontiersin.org/articles/10.3389/fped.2017.00121/full>
4. UK National Institute for Health and Care Excellence. Guideline: Myalgic Encephalomyelitis (or Encephalopathy)/Chronic Fatigue Syndrome: Diagnosis and Management. October 2021 <https://www.nice.org.uk/guidance/ng206/>
5. Centers for Disease Control and Prevention. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Information for Healthcare Providers: Severely Affected Patients. <https://www.cdc.gov/me-cfs/healthcare-providers/clinical-care-patients-mecfs/severely-affected-patients.html>
6. Dialogues of a Neglected Illness. Severe and Very Severe ME/CFS. 2020. <https://www.dialogues-mecfs.co.uk/films/severeme/>